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ABSTRACT

There is increasing conflict between the individual's right to privacy and the need for information about individuals by private and governmental institutions; these opposing forces need to be balanced. Two phenomena which have exacerbated this problem are the rapid advances in computer technology and the increasing demands of the individual on government and business. The United States Privacy Protection Commission made 162 recommendations to resolve this problem. Six guidelines applied specifically to educational researchers: (1) information gathered for research should not be used to influence decisions directly affecting an individual unless that person agrees; (2) disclosure of individually identifiable records may only be made under certain conditions; (3) no one should be forced to disclose personal information unless required by law; (4) a review process should be instituted to protect the individual's right to confidentiality against abuse; (5) if guidelines are followed, individuals should have access to their identifiable records when that information is used for purposes other than research; and (6) if information is disclosed without the assurance that it will not be used directly against the individual, the person should be notified and have access to the records. (MH)

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PRIVACY AND THE PROTECTION OF HUMAN SUBJECTS IN EDUCATIONAL RESEARCH

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PRIVACY AND THE PROTECTION OF HUMAN SUBJECTS IN EDUCATIONAL RESEARCH

by

David F. Linowes

Introduction

To set the subject of "Privacy and the Protection of Human Subjects in Educational Research" in proper perspective requires that I preface my paper with an overview of the informational privacy issue in our nation.

"As every man goes through life, " wrote Alexander Solzhenitsyn, "he fills in a number of forms for the record, each containing a number of questions....they are not material... There are thus hundreds of little threads radiating from every man." Then he goes on to describe how those who have access to the threads have the potential power to manipulate the man. It is essentially this aspect of relationships--informational relationships and their effect on personal privacy that the U.S. Privacy Protection Commission, which I had the honor to Chair, investigated over a two-year period.

No one is quite sure what we mean by privacy. There is no generally accepted definition. As a matter of fact, privacy rights are not specifically identifed in the Constitution, although the implication is clearly there. The Third Amendment prohibits the lodging of soldiers in private homes without the owner's consent. The Fourth Amendment protects citizens against

arbitrary government search. And courts have been interpreting a right to privacy from the Fifth Amendment which protects against self incrimination; the First Amendment which guarantees freedom of speech and assembly; and the Ninth Amendment which reserves to the people all rights not specifically delegated to the states and the federal government.

The Privacy Act of 1974 which established the Privacy Commission and placed certain constraints on federal agencies, for the first time gave statutory recognition to a right of privacy but did not define it. The Family Educational Rights and Privacy Act enacted in 1974 also established certain privacy protection safeguards without defining it. It gave a student or his parent the right to inspect and correct an education record about him, and gave the student some control over the disclosure of information from an education record.

Why this present, almost urgent, concern for an undefined right that has been considered only on occasion during the past hundred years?

Two phenomena in America are having a revolutionary impact on society: the rapid advances of computer technology, and the ever-increasing expectations of the individual from both government and business.

Technological developments have been so drastic that it is difficult for persons of our generation to comprehend them. Two thousand pieces of information are being stored on a silicon chip the size of the head of a pin. And, the cost of this storage has declined over 80% in the last two years alone. The power of silicon is so remarkable it is literally transforming society. Yet, next to oxygen, it is the most abundant element on earth.

Today, an inch-square "miracle-chip" has the calculating capabilities of an entire roomful of computer hardware of the 1950's. A million dollar computing capacity of three decades ago costs $20 today, and is 100,000 times faster. Work that required one day then, now is done in one minute.

By the end of this century the minuscule chip-based computer will be the single most significant technological force in existence. Throughout history societies have had to adjust when great technological breakthroughs had occurred. It happened with the invention of the printing press, the steam engine, the electric light, the automobile. One of the major convulsions in this generation is being triggered by computer technology. And, now we are just beginning to consider responding to it. Unfortunately, the law, and social mores have not been keeping up. Modern technology

seems to enable man to gain control over everything, except technology.

The other phenomenon, that of individuals demanding more and more from all institutions, continues to grow at what appears to be a never-ending pace. From Government we expect social security, unemployment compensation, guaranteed mortgage and education loans, and all levels of welfare. From business, we expect credit cards which give us instant credit approval any place in the world, and the ability to make plane reservations in a matter of minutes for any kind of trip to anywhere.

Administrators responsible for furnishing these services must satisfy themselves of your eligibility by demanding and getting much personal, often sensitive, information. Thus more and more confidential data is being injected into the stream of government and business, never to be destroyed.

General Informational Privacy Concerns

I have no doubt that everyone in this room appreciates the value of information about the desires and preferences, the personal characteristics, and the various situations of individuals in this country. This information, as you well know, has important social value --- serious public policy decisions, including education, not to mention the allocation

of government funds, are only as valid as the vast amounts of data on which they are based. It has monetary value --- when it is collected and analyzed, it can be sold as market research.

I am less sure, however, that you recognize the difficulty of balancing this generally legitimate need for data against the equally legitimate need to protect the privacy of our citizens, including students and faculty. The competition between these needs has always existed, but the necessity to address it is more urgent now than ever before.

One reason is that our appetite for information borders on the voracious. Social and educational institutions as well as consumer-oriented organizations have become more and more sophisticated. They want every detail they can lay their hands on, so as to be able to more clearly identify and reach their objectives. This makes good management sense.

Every American is the subject of one or more medical files. Who can argue against the need to keep such records when a person's medical history is essential information to an examining physician? Insurance companies surely have a real problem in trying to identify fraudulent claims. They have created an organization known as the "Medical Information Bureau," which serves as a clearinghouse for information among

some 700 companies. This bureau contains the medical records and "social data" on 11 million Americans, including information on their finances and even sexual habits.

Credit card systems are equally pervasive. Their data weaves through a person's life, linking together what he reads, where he travels, with whom he associates, what he buys.

All of these organizations hunger, with good reason, for some kind of information which has the potential of reducing their risks and aiding in decisions. And the government, the biggest data collector of all, is constantly collecting information so as to better shape public policy.

Another reason for this new sense of urgency is that the abuse of individual privacy is greater than ever before. Most organizations that seek to hire someone for an executive post obtain an investigative report on that person as part of its screening process. Many companies will get similar reports on current employees being considered for significant promotions.

Most employers provide group insurance plans for their employees. Since they generally administer the processing of claims, they have access to the details of an employee's medical treatment, and will often use it in making promotion decisions. This is an abuse of access to information which

should be highly confidential. Private investigators have been known to obtain medical records from hospitals and doctor's offices, sometimes under false pretenses, and sell the information to insurance companies.

And the long-held belief that a person's personal finances are nobody's business but his own is no longer valid. As banks have penetrated ever more deeply into the open-end credit field, the confidentiality of bank account records has been breached. As a result, these records find their way into the hands of employers, landlords, or independent authorization services which recognize no duty of confidentiality to the individual. And the situation for other types of credit-grantors is even worse. Independent credit-card issuers confirmed that as high as 99% of government agency requests for information are made informally --- either over the telephone or in an informal visit --- and are granted just as informally.

A third reason is that today's technology is light years beyond anything that existed even a generation ago with regard to the collection and analysis of information. Thanks to a tiny piece of matter called a silicon chip, thousands of bits of information can be stored on an area the size of a pinhead. Information about individuals

collected from a wide array of sources can, with ease, be compiled, matched-up and integrated into an unsettlingly detailed personal profile. This profile can be grouped with similar profiles, and the result is an easily-rentable list of names and addresses of people who are, say, liberals, or Republican "fat cats," or black activists, or all-American patriots. A person who subscribes to a magazine or buys a shirt through the mail today will be the unwitting recipient of 25 other solicitations within a year. And this profile can be transmitted with a lightening-quick speed all over the world, from one user to another to another, regardless of its accuracy.

Some of the stories about careless or irresponsible data collection, and the unhappy results that ensued, are enough to make the most secure of us become paranoid. A private investigator, taking the word of a spiteful neighbor in a very brief interview, almost wrecked a respected --- and innocent --- journalist's chance to have automobile insurance. Horror stories abound, but it is not the stories that you hear about that signal the threat. It is the thousands of stories that you don't hear because the victims never knew what happened. And most of those who did find out never had the perseverance, or time, or money to pursue the matter and obtain justice.

Unfortunately, information, good and bad, correct or erroneous, stays with us. As the technology has developed, it actually has become less expensive to store this information than it is to eliminate it.

The U. S. Privacy Protection Commission wrestled for two years with these kinds of problems --- the problems balancing the legitimate needs for information on the part of private institutions and government with the needs to protect the privacy of individuals. We heard from over 350 witnesses and compiled a stack of testimony eight feet high. In the end, we arrived at 162 recommendations that we believe strike a good balance.

There were three main objectives that permeated our recommendations: (1) to minimize intrusiveness into the lives of individuals, (2) to maximize fairness, and (3) create legitimate enforceable expectations of confidentiality. All of these have tremendous bearing on the work that you do.

Recommendations Applicable to Educational Research

Some of those recommendations included guidelines (six) that dealt specifically with the research community. These I shall summarize and comment on:

First, we recommend that records and information gathered for research purposes should never be used to

influence any decisions or actions directly affecting one of the individuals surveyed, unless that person so authorizes its use. Research organizations should establish a special set of rules to ensure that this won't happen. This means that there should be technical, administrative, and physical safeguards against unauthorized or inadvertent disclosure, and the information should be rendered anonymous by being stripped of identifiers as soon after collection as possible.

Second, that the organization conducting the research may only disclose individually identifiable records without the consent of the individual identified if certain conditions are met. The conditions include that such disclosure is necessary to accomplish the purpose of the undertaking; that the disclosure yield enough social benefit to warrant the increase in the risk to the individual of such exposure; that the above-mentioned safeguards against unauthorized disclosures are established; and that further use or redisclosure without the express consent of the individual identified be prohibited.

Third, that no one should be required to divulge information about himself for a research or statistical purpose unless the law requires otherwise. To insure this, the individual should be informed that his participation is

at all times voluntary, what the purpose and nature of the data collection is, whatever possibility there is that the information may be used in individually identified form for any additional purposes, research or not, and that if disclosure for purposes other than research is required, he will be promptly notified.

Fourth, that there be a review process or a special representative in any research organization responsible to apply the above principles in special cases, specifically, in order to protect people who are not competent to give informed consent (for example, minors or mentally incompetent individuals) or people who may be reluctant to give consent for fear of some loss of benefit or some potential retaliation (for example, prison inmates, employees, welfare recipients, or students). Also, this process should provide safeguards in cases when the research requires that the people being studied be unaware of the existence, purpose, or specific nature of the research.

Fifth, that if and when the above guidelines are followed, an individual should have access to whatever information is used or disclosed in individually identifiable form for any purpose other than a research or statistical one (for example, an inadvertent unauthorized disclosure). Fairness demands that people be able to find

out what individually identifiable information about them has been made. Of course, the research organization should keep an accurate accounting of all such disclosures.

Finally, that if any of the records or information I have been talking about is disclosed without an assurance that it will not be used in any decision or actions directly affecting the individual concerned, or without a prohibition on further use or disclosure (for example, to a court or an audit agency), the individual should be notified of the disclosure and of his right of access to the record.

We found it necessary to make the foregoing recommendations because our investigations revealed that several disturbing phenomena currently pervade research activities.

*Research is becoming increasingly dependent on information originally collected for administrative purposes. This weakens the individual's ability to control or even express a preference about the way information about him is used and disseminated.

*The expectation of confidentiality in research and statistical activities becomes increasingly questionable as the number grows.

*The use of individually identifiable information for administrative, regulatory, or law enforcement purposes encourages abuse of the expectation that the material will be kept confidential.

In most studies, the researcher is interested in the individual insofar as he represents a group of people, and data are generally presented in aggregate form. However, when researchers, statisticians, and clerical personnel work with individual records, the risk of breaching privacy by unauthorized dissemination always exists.

Conclusion

What are the interests on both sides here? In the case of all three of the general principles which I mentioned earlier --- to minimize intrusiveness, to maximize fairness, and to respect confidentiality, the research organization and the individual actually have mutual basic interests. They both want to curb the tendency to accumulate or spread any more information than is necessary. It is a financial burden on the organization to collect and maintain more information than it needs, and it is dangerous to the individual to have intimate details of his personal life piling up in an organization's files.

Further, it benefits both the organization and the individual that the records be as accurate, complete, and up-to-date as necessary. Neither stands to gain from inaccurate, incomplete or obsolete information.

As for confidentiality, the Commission recognized that it may be a bit too wishful to expect all research organizations to honor an obligation of confidentiality solely

because that which is breached one day in your favor, may tomorrow be your undoing. So we recommend that, aside from specific exemptions, there be a liability in the form of monetary sanctions on organizations which violated the expectations of confidentiality. These sanctions range from court costs and actual damages to --- in cases of willful or intentional violation --- general damages of between $1,000 and $10,000.

You may not feel comfortable with all of our recommendations and guidelines. Adopting them may create additional administrative burdens, and costs. But it is our conviction that positive steps need to be taken now, and that we must all share the burden in order to achieve a goal that is even more valuable to all of us --- the preservation of a democratic free-enterprise society.